

Belonging Matters' Submission to the NDIA

Home and Living consultation: An ordinary Life at Home

September 2021

Part 1: Summary

In this submission, we have provided a brief overview of Belonging Matters, our work, some of the barriers people with a disability face in regard to securing an ordinary home life (gained from nearly 20 years of supporting people with intellectual disability and Autism), some reflections from a recent consultation with people with intellectual disability and family members, as well as some recommendations about what needs to change to enable more people with a disability to achieve an ordinary home, and life at home in which they can enjoy and thrive. These include:

- Everyone has a right to an ordinary life at home, even people with complex needs.
- People do better when they live in their own home, that is uniquely tailored to their preferences and needs
- The need for capacity building, and maintaining a vision for an ordinary life.
- Reflections on good capacity building.
- Ongoing capacity building investments in the sector which promotes and flourishes individualised supported living models and stimulates innovation.
- Enabling and supporting individualised transitions to living in one's own home and recognising that as with most citizens, finding a home is not a one-time occurrence, it's an ongoing journey.
- Planning that is an individualised, ongoing, supportive process built around each person with a disability, families and supporters to explore, design and maintain individualised supported living.
- Recognising that it's not enough to have a home, all people need a life embedded in community, contribution, purpose and relationships.
- Investment in new and innovative housing models, including support for homeshare and shared equity schemes.
- An investment in individualised supported living leadership and a commitment to transition from congregate living.
- Access to independent capacity building supports, skilled advocacy and knowledgeable mentors with a sound understanding of individualised supported living for people in group homes especially those who have few informal supports.
- Strengthening the NDIA's Individualised Living Options (ILO) framework and funding through engaging co-designers and leaders in the area, who understand what it takes to make individualised supported living work.

- Supporting the leadership of people with a disability and their families to share their stories and insights about having valued lives in ordinary homes.

Part 2: About Belonging Matters

Belonging Matters is a not-for-profit capacity enhancing service that provides education, resources, mentoring and advice about social inclusion and belonging. It was developed in 2003 by people with disabilities and families who have a passion for social inclusion! We are people friendly and value driven.

Supports we provide

Belonging Matters undertakes a range of activities and produces a range of resources that aim to inspire and build the knowledge and skills of people predominantly with intellectual disability and Autism, their families and allies to enable people with a disability to have opportunities and pathways typical of other citizens in the community - lives that are personally fulfilling, unique, socially inclusive and empowering.

We also provide personalised mentoring to enable people to create a vision for a good life in the community and plan for what might be needed to make it a reality. We are available to people over the long term as life changes, but by building the capacity of people themselves, this becomes less frequent.

Belonging Matters also invests in the leadership of people with a disability to mentor others and share their story. This is often a key to others creating change as they can see it can be done.

What informs our work with people with a disability and families

Our work is informed by the lived experience of people with a disability and families through our board membership, feedback mechanisms and Belonging Matters Advisory Council and consultation work. The work of Belonging Matters has been informed by many leaders both nationally and internationally. Our organisation is a member of the National Alliance of Capacity Building Organisations (NACBO). At its foundation, Belonging Matters is guided by Social Role Valorisation (SRV). This informs us about why and how people are marginalised in society and what means we can use to address devaluation and marginalisation. A key means is through affording people with a disability access to the same opportunities and valued roles as everyone such as a home of their own and paid employment.

Contact

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Part 2: Where are we now?

“There are approximately 1.1 million Victorians living with a disability. In 2018-2019, over 5,000 people with disability were living in ‘residential services’ as defined in the Disability Act. 86 percent of residents living in supported accommodation have an intellectual disability as their primary disability. Group homes are the dominant form of housing chosen for people moving out of large institutions and for people who do not have the choice to live with their family”. (Royal Commission Public Hearing Report 3, page 11).

Although practices vary across group homes, with some providing more positive environments than others, the Royal Commission evidence illustrates how people with a disability living in congregate care are experiencing an array of common negative consequences. They included:

- Significant lack of control over many aspects of their life.
- Lack of control over who enters their home.
- The living situation is compromised by competing needs of residents.
- Lack of privacy.
- A lack of choice about where you live, and who you live with, including significant compromises in compatibility, and at times, detrimental consequences for wellbeing and safety.
- Lack of choice about who provides supports and ‘closed system’ situations where a person has multiple support types provided by the one agency.
- Rigidity of routines that are not flexible around individual needs and are staff and agency centred, rather than person centred.
- Denial of basic choices, such as food, the times someone can go to bed and even when they can use the bathroom.
- Houses that look and feel like institutions, not like homes.

(Royal Commission Public Hearing 3 Report p 67 - 71).

Part 3: What needs to change?

Everyone’s right to an ordinary life at home, even people with complex needs

Underpinned by key legislation such as the UNCRPD, we need to start from a position that, regardless of a person’s type or level of disability, they have the right to choose a comfortable and nurturing home where they experience freedom and autonomy. If

choosing to live with others, people should be surrounded by those they have chosen, are a good match and are not limited just to people who share the same diagnosis. People also need individually tailored, developmental and flexible supports to meet their needs and enable them to live well.

There needs to be a change in mindset where assumptions about some people with a disability, particularly those with more complex needs, are 'unsuitable' for anything other than group homes. Sharing stories of a range of people living successfully, including those with more significant needs, will be an important strategy in changing current thinking.

Recently an advocate engaged Belonging Matters in regard to a man with intellectual disability who was very keen to move into his own home away from a group home. The staff of the group home were adamantly opposed to this idea and enlisted the opinion of a GP, who determined that the person was not suited to a living option outside of congregate care, without even having a conversation about individualised supported living.

"The doctor doesn't have experience around how moving out of home can work...it's all medical model thinking... one reason put forward was you can't get health care in your own home, you can only get it in a group home."

This is not to say that there is not a role for some professional opinions in the lives of all of us, however, for people with a disability these opinions can almost become like a law, governing the whole extent of what is seen as possible for the person and their whole life.

A comprehensive report based on meta-analysis of literature and broad ranging consultation with people with a disability, families, advocates and peak bodies, as well as specialist agencies, reported on the elements of success in designing and implementing independent/individualised living options and supports for younger people with a disability. The report states

"There were key elements to effective housing and support for people with disabilities. These were accessible homes in central locations, homeliness and privacy, clear rights and responsibilities, consumer control, individualised arrangements, flexibility of support, protection and enhancement of informal relationships, a sense of belonging to a community, responsive services and personal safeguards" (Taleporos, et al, p6). We would encourage the NDIA to review this report. [HOUSING AND SUPPORT FOR YOUNGER PEOPLE WITH DISABILITIES TRANSITIONING TO INDEPENDENT LIVING: \(individualised living.com.au\)](#)

Well planned and supported housing options tailored to individuals, with sufficient supports inbuilt, have been shown to be successful in enabling positive outcomes for people, even those with complex needs. [The Quality and Outcomes of Individual Supported Living \(ISL\) Arrangements for Adults with Intellectual and Developmental Disabilities](#) (Cocks, et al 2018) undertook 3-stage longitudinal study including the review of 130 ISL's across Western Australia, New South Wales and Victoria, of people with developmental

disabilities living in their own homes. The study found a range of benefits for individuals, in individualised supported living arrangements including the potential for people's networks and friendships to expand. Likewise, while the study found 'host' arrangements relatively uncommon, they described some of the outcomes of these as 'quite impressive' (p14). The study found that 'participants did the things that other people do in their homes, and their homes reflected (their) personalities' (p19).

The researchers also stated *"adults with all levels of support need can be supported to live in an ISL arrangement. One quarter of participants reported high support needs, half had moderate support needs, and the final quarter had low support needs. The support participants received ranged from minimal drop-in assistance of less than one hour up to 233 hours of paid and unpaid support per week."* (Cocks and Thoresen, 2017, p3)

The study also found that not all ISL's were equally successful in the outcomes they enabled for people. The study found there are key features that support the effectiveness of ISL such as leadership, my home, one person at a time, planning, control, support, thriving and social inclusion. McVilly et, al (2017) summaries these key themes and attributes in this brief article, [You Can't Solve Homelessness Through Housing Alone](#). These key features are also illustrated in Cameron's story ["A Home of My Own"](#)

Capacity building, and maintaining a vision for an ordinary life

People with disabilities are subject to widespread disempowering beliefs about what is possible for their lives. The consultation paper aptly names the experience of 'chronic disempowerment'. The NDIA, Independent Advisory Council (2015) stated that Capacity building is crucial in enabling people with a disability to engage in their community & reduce reliance on services.

We have found that education, capacity building and reflective practice is needed to empower people with disabilities, families and professionals to imagine alternatives to congregate care. The service system perpetuates the notion that people with a disability need to live with others with disabilities and 'in care'. Capacity building is a powerful mechanism to open people's vision as to what is possible in regard to an ordinary home and life. It also challenges myths, assumptions and bias. Without concerted efforts to share, maintain and enact this vision, it is too easy for people to enter into or remain long-term in segregated housing, believing nothing else is possible.

As part of our submission, we asked people with intellectual disability living in their own home why this was important

"I can just do what I want - I have more freedom".

"I can have my own space and just be me".

"It just feels cozy, and it has good surroundings."

People also emphasised that home should be a place where people are able to grow, develop and become as independent as possible.

“People, once they get into a home, they should be able to do things, like cook for themselves.”

“I’ve grown up a lot, I pay my own bills, do my own laundry.”

“I have chosen what my home looks like.”

“I can do what I want, (when I want) watch TV, go out, stay up late.”

Such ordinary things are what most Australians would consider minimal standards and rights. However, these ordinary and typical experiences are often not the experiences of Australians with disabilities in congregate living because there are too many competing agendas and needs.

Belonging Matters believes in good reflective practice i.e stepping into the life of a fellow human being. This practice helps us to prevent the risk of further wounding people with a disability and offering people alternatives that are not valued or typical or that we would simply not accept. For example, ‘would I be happy living in a similar situation or spending my time in a similar way to this person with a disability?’ ‘Is this activity, pathway or experience typical? Does it represent what others without disabilities experience?’

A sibling commented on the importance of capacity building when assisting his brother to move from a service arrangement into his own home:

“I really agree about just the sheer, just how dominating some services can be, they have clear conflict of interests, as well making decisions supposedly in the best interests of a person...we were basically told that my brother would end up in a group by almost every service provider, It really just took kind of seeing alternative models like proposed by Belonging Matters. And then, one of his family members, me, just advocating and advocating and pushing back against this dominant best interest approach that they sort of pretend is neutral and comes from a place of professional, you know, evaluation, but is actually just an opinion that's really just based in in very negative messages about people with disabilities

“It was so important to have those conversations (about an ordinary life) to counter the negative messages we had been given, all my brother's life.”

Good capacity building:

- Involves people with disabilities and families sharing their stories about living in their own home with a range of in/formal supports.
- Engages and supports the leadership of people with disabilities and their families.
- Listens deeply to people and is about ‘walking with them’ as unique human beings over time.

- Has strong, clear, principled leadership at all levels to enable people with a disability to have full, meaningful, personally relevant and inclusive lives.
- Shows people what is possible and it holds firmly to a vision of typical home and home life and does not give in to bureaucratic or system compromises.
- Assists **each** person to develop their own vision and live in their own home, one person at a time.
- Breaks down and addresses fears.
- Challenges deeply held beliefs and damaging stereotypes.
- Celebrates the positive.
- Is a continuous journey, not a one-time occurrence.
- Makes good practice widely and practically understood within organisations and the sector.
- Considers risk aversion so it doesn't trump the opportunity for a good life but rather asks what safeguards need to be in place to enable this person to live in their own home.
- Shares knowledge and succession planning so that wisdom and good practice doesn't depend on the presence of a few people.
- Recognises the realities of the lives of people with disabilities and the ways people are disempowered and offered options that are not typical or valued.
- Understands the impact of services and that the over dependence on paid supports can be isolating, disconnecting and disempowering.
- Engages those with the power to make change to understand why a change journey is urgently needed.
- Understands and reveals the limitations and impact of segregation and congregate care .

Investments in the sector

Much of the innovation in regard to individualised living arrangements has been driven by people with a disability and families. There is very little service innovation that is guided by the themes and attributes outlined in the ISL research. We do not mean “drop in” support but services with vision, who can not only assist people to imagine, plan and move into their own home, but engage a range of support and relationships (not just paid) and assist the person to think about how they contribute to the social and economic fabric of their community.

Grants and financial support that stimulate good practice, exploration and innovation in regard to individualised support living may stimulate and support leadership examples.

One model, for example, that we have found particularly useful for people with intellectual disability is homeshare. Homeshare has a long history and is based on an exchange of social capital i.e. ‘I have a room in my house and I invite you to live rent free in return for

support and/or companionship'. This model is extremely useful for people who require 24 hour support and it avoids costly formal supports. It also offers a more natural relationship. Yet there is little investment and exploration of this model. Also, restriction and confusion about how NDIS funding can be used. For example, it can pay the homesharer but not the homesharer's portion of the rent directly to the landlord in lieu of support. Although the new Individualised Living Options (ILO) funding might support this model, few planners are aware of it and there is much confusion about the NDIA's policy in regard to rent reimbursement. For the amount that makes rental and support affordable in a homeshare arrangement, it is often a stumbling block for the NDIA and planners. Yet, in comparison, SIL arrangements that cost so much more are widely supported.

Support agencies, planners and even NDIA staff need to be equipped to assist people with a disability to explore a range of housing options that afford people the same opportunities in regard to home as other Australian citizens. It is not enough to rely on uniformed choice. People need the exposure and opportunity to explore a range of options and not be pigeon holed into congregate care.

A person with an intellectual disability, who was supported by Belonging Matters, when asked what kept him from initially speaking up about a living situation and day to day activities that he was very unhappy about, said he wanted to *please others* and agree with them. It was not until this person had the support of those who believed in individualised supported living and an inclusive life that they felt able to speak up strongly. He has now lived in his own home for nearly 20 years!

A participant in the housing and supports research focused on young people also poignantly said

"Group homes are for parents, but they don't have to live in one." (Taleporos, et al) p31

Enabling a transition to living in one's own home and the right to housing journeys

People with a disability are also less likely to experience housing 'journeys' in the same way that other Australians do, including having the opportunities to experience and enjoy different housing options, reflecting different opportunities, preferences and stages of life. The complexity of housing generally, and particularly for people with disabilities means that once a housing 'solution' is found, people often remain there for long periods of time or their entire lives. People with disabilities should have opportunities to experience a range of preferred living options throughout their life.

The importance of 'trailing or tasting' also cannot be underestimated in enable a person to move into their own home. Many people, both families and people with a disability associated with Belonging Matters talk about the importance of a staged approach to moving out of home e.g. staying in their new place a few nights per week, staying at an Airbnb for a short period or at the home of a friend or extended family member. This enables the person to trail, discover might be needed, live away from the family home and

build skills and confidence. Similar strategies were employed by some families involved in the other research cited. Without enhanced ability for NDIS funding to enable people to trial and taste, their housing journeys can be stifled.

Planning is an ongoing, supportive process built around people with a disability, families and supporters

Planning processes in the context of the NDIS are undertaken within a very limited timeframe, with significant decisions around a person's life often made with strangers within the context of a one-hour planning meeting. These meetings are facilitated by a planner who, may aim to introduce new concepts and opportunities to the person with a disability and their supporters, knows little or nothing about the person and their life. They are also lacking the opportunity to build the critical high level of trust and nuanced knowledge that is necessary to help understand what is needed, and what is possible for someone.

Planning needs to occur continuously over a significant period of time and should not be led by time-pressed paid professionals. Planning needs to deeply engage and enable the people who most love and care about the person, while keeping the wishes, preferences, dreams and voice of the person at the centre, and working in ways that enhance that person's voice. These invested people are most often close friends and/or family, but they also must be those who are able to imagine, or be skillfully supported to imagine, a good life.

A person with a disability told Belonging Matters – *“it’s sometimes good to have family that is not your immediate family, like your uncle or your aunty [involved in helping you build a good life]. Mum and Dad often think they know best but sometimes they just don’t listen.”*

When wanting to move into her own home, this person said *“sometimes Mum and Dad just needed a push from someone outside”* (Referring to the facilitator of her Circle of Support).

Both the above quotes point to the need for skilled facilitation of planning, especially when this involves significant decisions or transitions. This role may be paid or unpaid, but requires someone who is truly invested in a good life for the person and has the requisite set of skills and time to enable and engage others.

The consultation paper cites the importance of advocacy, as well as peer support and both these support structures will play a critical role for many people in the NDIS, particularly, as is mentioned, for those people with a disability who have limited or no informal supporters. However, where the person is in need of significant support to make progress towards their goals, there also needs to be a mechanism for key supporters to come together regularly around the person and help them enact the life they are wanting to create. Well informed and facilitated Circles of Support are one effective mechanism for enabling support around a person with a disability to progress towards their goals, if they

have vision and are used well. Whatever the mechanism, it needs to uphold the person and the sanctity of home and not be dominated by service rules and regulations.

It's not enough to have a home – But a life embedded in community and relationships

“There needs to be a much richer understanding of what home is - a richer understanding by LAC's, planners, families, people with disabilities, service staff.”

“That home is about a sense of belonging, having connections, being known and involved in the local area, being near amenities and being able to come and go and get around easily and safely, having people you can call on, knowing neighbours, knowing where the safe and friendly places are.”

Reflecting on his journey with Belonging Matters, one person with a disability spoke about his experience of moving from a bungalow at the back of the family's rural property into his own home in the heart of community.

“I was isolated, a bit depressed. I didn't have work; I went to a day service and didn't like it. I didn't have many connections. I have been able to turn my life around, I have work, I have worked for 16 years, I volunteer at a farmers market, I have friends, people from my high school, we catch up.”

It is crucial that alongside planning and visioning around home, there is an investment of time, money and energy into thinking about and helping people build informal supports, valued roles and connection to the neighborhood and community. Having roles of contribution makes us feel valued and opens up our networks. Being well known and connected with neighbours and other community members provides an important safeguard e.g.. neighbours checking up on each other during COVID.

It's simply not enough to have a roof over one's head. Human beings need connection, relationships, purpose and opportunity to contribute to the lives of others in their communities.

Investment in new housing models

The sentiments and proposed actions within the consultation paper outline some positive and concrete steps to achieving greater housing choice and better homes for people with a disability. However, new individualised home support models, including ILO, must be sufficiently understood and funded to be successful and incorporate the supports people need. Without adequate understanding and investment, these arrangements can break down or in other ways are unsuccessful.

ILO represents a critically important ideological shift which says that people with a disability should experience home life in ordinary and typical ways, rather than in specialist settings, and tries to make this vision a reality with each person. If early ILO's are unsuccessful, it will have a range of negative consequences such as lack of confidence in

the model by people with a disability and families, lack of confidence in providers or potential providers and negative impacts on people with a disability and their supporters, who with great courage and hope are creatively leading change. The cost of group home living is very high. (The consultation paper indicates that “*when SIL payments were at their highest (Quarter 4 2019-20), the average annual cost of SIL was \$325,000 per participant.*” (NDIS Consultation Paper: An Ordinary Life at Home, page 12). The investment and leadership in ILO is crucial and implemented well, can contribute to better outcomes and reduce the costs to the scheme.

Increasing housing affordability

Housing affordability is an issue for all people, however if people do have access to paid employment, then they don't have the same means to afford rent or a mortgage. Innovative schemes like *shared equity* give people the opportunity to eventually pay off a home. Yet, this scheme is severely under-resourced. Homeshare arrangements, with income earners, can make rental more affordable as a person's support cost and rent can be offset. Capacity building for people and families about trusts and home affordability is vital along with investing in and supporting people with an intellectual disability in mainstream employment.

An investment in leadership and a commitment to transition from congregate living

In Australia, we see very few efforts to transition people with a disability out of congregate living, which are now represented by existing group homes. If we believe in equality and people's basic human needs to have a real home (not a service), then the dismantling of the congregate care system needs to be a priority. The following provides some recommendations to extend this work:

- Develop clear policy direction.
- Learn from and harness the leadership of those who have created ISL. There are many good examples throughout Australia of individualised supported living arrangements.
- Foster leadership in regard to ISL.
- Fund and support good innovative ISL demonstration projects, by leaders with vision and positive values as a catalyst for further progress.
- Support people with a disability and their families to share their stories.
- Set timelines in regard to transforming outdated congregate care models.
- Incentivise and support services to invest in service transformation, away from congregate care models.

Access to independent advocacy/skilled and knowledgeable mentors and capacity building supports for people in group homes especially those who have few informal supports

It is vital that people with a disability who are the most isolated, such as those who have no family and few or no informal supporters, are provided with more support to be able to understand and consider their choices in regard to key areas of life, such as where they live. Participants with little or no informal support should be identified as a priority and be supported to enter into conversations about their options. This work will need to occur over time, so people should be given the opportunity to link with independent advocates or mentors who can support them over a significant period. Options for building people's informal networks should also be considered in this work.

Stories and examples of what works and understanding what it takes

The consultation paper makes clear that the sharing of stories about successful individualised living options will be an important part of the work to help encourage and support more diverse and positive homes being created with people with a disability. Positive stories will be an important part of encouraging a range of stakeholders to consider and pursue ILO housing options. Likewise, demonstration projects that illustrate the diversity of ILO will be an important way for people with disabilities, their supporters and the sector to better understand and feel confident about the possibility of this type of housing.

However, this also needs to be supported by a deep understanding by the Agency and providers and families about 'what it takes' to successfully implement and maintain a wide range of ILO's. Broad ranging consultations and conversations with people with a disability and families who are successfully making ILO's work are needed, as well as the engagement of providers who have an established history in good quality individualised supported living. This could provide an understanding of what it takes, including for example, successful examples how each person is assisted to plan and move into their own home, successful planning for contingencies, what constitutes sufficient time and capacity to coordinate ongoing supports, elements that are needed to enable stability in the running of the ILO (for example certainty and continuity of funding), reflection and renewal.

Stories of people having valued lives in ordinary homes

As part of the [National Alliance of Capacity Building Organisations \(NACBO\)](#), Belonging Matters contributed to a submission to the Royal Commission published in June 2020 called [The Meaning of Home](#). This outlines 20 stories of people with a disability living in their own homes. The submission highlights different areas of best practice that enabled people to move into their own home. We would like to refer the NDIA to this document as it provides a range of examples of successful contemporary housing models.

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